

Quality of Life and Survivorship



Quality of life is a standard throughout the cancer care continuum – from diagnosis to remission, cure, or end-of-life. It includes active treatment, survivorship, rehabilitation, palliative care, and hospice. Palliative care identifies and addresses the physical, psychological, spiritual, and practical burdens of illness. It is offered by an interdisciplinary team that includes medical professionals, social services, spiritual

The goal of palliative care is to prevent and relieve suffering, supporting the best possible quality of life for patients and their families throughout the continuum of disease. It is both a philosophy and an organized, highly structured delivery system.

advisors, and others. All are focused on the relief of suffering and on supporting the best possible quality of life for patients facing life-threatening illness and their families.

Though research indicates that cancer patients' pain and other symptoms often are not well

controlled, good symptom management can contribute to improved quality and length of life. Medical literature suggests that patients and families may have better outcomes if they are able to understand and direct their care. In addition, many patients express the need to maintain control over their care and feel that it improves their quality of life and survivorship. Many cancer patients rely on spiritual or religious beliefs and practices to help them cope with their diseases. Some patients may want their doctors and caregivers to acknowledge their spiritual concerns, not only for end-of-life issues but also during treatment. According to the Institute of Medicine, quality end-of-life care should include pain management, psychosocial support, and timely referral to hospice.

Increasingly, patients are using complementary and integrative medicine, which support and are used in

conjunction with traditional, evidence-based treatment. Complementary therapies might include such activities as acupuncture, massage, meditation, music therapy, or biofeedback. Cancer patients should have access to all forms of therapy from which they can benefit. Integrative medicine is a total approach to medicine that involves mind, body, and spirit. For example, relaxation might be used as a way to reduce stress during chemotherapy.

Childhood cancer brings with it a host of issues that affect the entire family. Having cancer can bring physical, emotional, and cognitive changes that affect a child's ability to perform. Even so, returning to normal routines as quickly as possible can provide a sense of purpose and hope to the family.

Nationally, the number of cancer survivors tripled between 1971 and 1999. There were 9.8 million survivors in 2001.

Quality of life: The individual's definition of what is acceptable physically, psychologically, and spiritually.

Stages of Grief

Elizabeth Kübler-Ross originally defined the stages a person goes through after learning of a serious illness, suffering a loss, or a major life change.

1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance

Goal I: Promote quality of life for cancer patients.

Objective I.1: *Increase the percentage of hospitals that offer pain management programs for cancer patients.*

Baseline: Twenty-four percent of Montana hospitals reported pain management programs (*Last Acts: Means to a Better End. A Report on Dying in America Today* 2002. Montana)

Outcomes: By 2011, increase the percentage of hospitals offering cancer pain management programs to 50 percent

Data sources: Hospital survey

Strategy 1	Determine the percentage of hospitals offering pain management programs.
Strategy 2	Support the cancer-related activities of the <i>Task Force on Pain and Symptom Management</i> recognized by the Montana Legislature. Consider the task force's recommendations on pain and symptom management interventions, use of complementary medicine, the needs of the medically underserved, drug repositories, and end-of-life cancer pain treatment. Consider the task force's analysis of state statutes.
Strategy 3	Promote pain management standards and develop an implementation plan for increasing the number of cancer pain management programs.
Strategy 4	Educate the healthcare provider and patient communities about standards related to cancer pain management.

Montana has palliative care programs in most major cities. Two meetings have been held to initiate communication and facilitate cooperation among these programs.

Pain Management: There are disparities in access to effective pain management for special populations, particularly racial minorities, children, and the elderly. For example, research indicates that nearly one-third of children's cancer centers in North America did not use general anesthesia or deep sedation for the majority of bone marrow procedures, and more than 25 percent used either nothing or topical anesthesia (*Pain Information for Professionals*. American Cancer Society: www.cancer.org).

Palliative Care: Palliative care and symptom management is medical care that lessens pain or the effects from treatment of a disease, such as cancer. It helps to make patients more comfortable at every stage of illness. It is also referred to as supportive care.

Palliative Care Guidelines: There are now practice guidelines for quality palliative care established through the *National Consensus Project for Quality Palliative Care*. These will set the standard for palliative care programs across the nation. The guidelines describe core precepts for clinical palliative care programs.

Aspects of Care	Psychological and psychiatric	Physical	Social and cultural	Spiritual, religious, and existential
Structure and Processes	Care of the imminently dying patient	Ethical and legal	Adapted from: www.nationalconsensusproject.org	

Objective I.2: *Increase the percentage of hospitals offering palliative care programs that address cancer and treatment symptom management.*

Baseline: Sixteen percent of hospitals reported palliative care programs (*Last Acts: Means to a Better End. A Report on Dying in America Today* 2002. Montana)

Outcomes: By 2011, increase the percentage of hospitals reporting palliative care and symptom management programs for cancer patients to 30 percent

Data sources: Hospital survey

Strategy 1	Determine the percentage of hospitals offering palliative care and symptom management programs.
Strategy 2	Ensure that cancer survivors across Montana have access to palliative care, symptom management, and hospice programs.
Strategy 3	Promote national palliative care standards and develop an implementation plan to increase palliative care programs that address symptoms during cancer treatment for cancer survivors of all ages.
Strategy 4	Encourage palliative care programs to include routine recommended order sets for symptoms associated with cancer treatment, as based on National Hospice and Palliative Care Organization (NHPCO) and American Society of Clinical Oncology (ASCO) guidelines.
Strategy 5	Develop and implement a plan for palliative care programs that includes appropriate use of rehabilitation services designed to improve cancer survivors' quality of life.
Strategy 6	Educate healthcare providers and cancer patients, including children, about symptom management, palliative care, and hospice programs.
Strategy 7	Identify availability of hospice care in rural areas, assess gaps in availability and barriers to accessibility and utilization; design and implement strategies to improve availability, accessibility, and utilization.

***Hospice:** A model of care that can be delivered in a variety of settings, and which employs pain and symptom management within a defined end-of-life period of less than six months.*

Follow-up Care

It is natural for anyone who has completed cancer treatment to be concerned about what the future holds. Many people are concerned about the way they look and feel, and about whether the cancer will recur. They wonder what they can do to keep the cancer from coming back. They also want to know how often to see the doctor for appointments, and what tests they should have. Understanding what to expect after cancer treatment can help patients and their loved ones plan for follow-up care, make lifestyle changes, and reach decisions about quality of life and finances.

Follow-up care involves regular medical checkups that include a review of a patient's medical history and a physical exam. It is important because it helps to identify changes in health. The main purpose is to check for the return of cancer in the primary site (recurrence), or the spread of cancer to another part of the body (metastasis). Many times, recurrences are suspected or found by patients themselves between scheduled checkups. It is important for patients to be aware of changes in their health, and to report any problems to their doctors. The doctor can determine whether the problems are related to the cancer, the treatment the patient received, or an unrelated health problem. For more information, visit: <http://cis.nci.nih.gov/fact>.

Goal II: Empower cancer survivors and their families to maximize control over their lives and the disease through the appropriate use of resources and deliberate end-of-life decisions.

Objective II.1: *Identify and add to the cancer quality of life resources available to survivors, families, and employers. Help ensure their ability to identify their roles, responsibilities, and rights.*

Baseline: A comprehensive cancer quality of life resource list is unavailable

Outcomes: By 2008, a quality of life resource list will be available to cancer survivors, their families, and employers

By 2011, the level of resources will increase by a percentage to be determined once a baseline has been established

Data sources: Process evaluation results; quantitative evaluation results comparing baseline resources with those available in 2011

Strategy 1	Identify resources that describe roles, responsibilities, and rights attendant to cancer care and quality of life. Create a database designed to educate cancer survivors, family members, and employers. Add the quality of life resource list to the <i>Cancer Resource Roster</i> on the Cancer Control webpage.
Strategy 2	Add the resources available to facilitate access to psychological, physical, social, emotional, vocational, economic, and spiritual support services to the cancer quality of life resource list.
Strategy 3	Analyze gaps and barriers to quality of life cancer services, and implement strategies to overcome them.
Strategy 4	Develop and distribute new and existing resources including patient educational materials, roles and responsibilities, treatment options, common symptoms management, patients' rights, legal, and ethical end-of-life options.
Strategy 5	Increase awareness and encourage expansion of support groups as a tool to help survivors and their families meet their psychological, physical, social, emotional, vocational, economic, and spiritual needs.
Strategy 6	Promote outreach to improve access to these support groups for survivors, families, and employers in smaller communities.
Strategy 7	Make information on return-to-work and other aftercare issues available to survivors.

While it may be reasonable to hope for a long life, it is also possible to hope for different things — being comfortable...being supported by loving care....having the time to review the past and to take pleasure from it...taking the opportunity to resolve problems and to continue to love and be loved. — adapted from the National Coalition for Cancer Survivorship

The Americans With Disabilities Act (ADA) calls for employers to provide “reasonable accommodation” for workers with disabilities, which may include anything from special equipment or lighting to flexible schedules. The Family and Medical Leave Act (FMLA) requires many employers to allow unpaid, job-protected leave. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) has helped ensure that pre-existing conditions may not be excluded in certain new health policies if gaps in coverage are relatively short.

Objective II.2: *Increase the number of cancer patients who have access to advanced healthcare directives through their healthcare providers.*

Baseline: To be determined

Outcomes: By 2008, determine the number of healthcare providers who make advanced healthcare directive planning available to their cancer patients

By 2011, improve the number of healthcare providers making advanced healthcare directive planning available by a percent to be determined

Data sources: Healthcare provider survey

Strategy 1	Determine the baseline number of healthcare providers assisting with advanced healthcare directive planning.
Strategy 2	Review and assess the status of Montana State Law pertinent to advanced healthcare directive planning.
Strategy 3	Work with the Palliative Care Summit Workgroup to develop strategies that will encourage healthcare providers to make advanced healthcare directive planning available to their cancer patients.
Strategy 4	Educate healthcare providers about the availability and use of advanced healthcare directives, including living wills, Durable Medical Power of Attorney forms, <i>Five Wishes</i> , and the Montana Choices Bank Repository Act, a voluntary registry for consumers who wish to ensure that their healthcare providers have access to their advanced healthcare directives.
Strategy 5	Identify and review problems with <i>Comfort One</i> and consider implementing a Physician Orders for Life Sustaining Treatment (POLST) form similar to those used in Washington, Oregon, and West Virginia.

Objective II.3: *Develop and communicate a Patient's Bill of Rights for cancer care.*

Baseline: A standardized Patient's Bill of Rights for cancer care has not been developed

Outcomes: By 2008, determine baseline data on the status of a Patient's Bill of Rights in Montana

By 2011, begin promoting a standardized Montana Patient's Bill of Rights for cancer care

Data sources: Process evaluation results

Strategy 1	Gather and review Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards for Patient's Bill of Rights; review the status of Montana state laws as well as clinical standards recommended by the National Consensus Project for Quality Palliative Care.
Strategy 2	Draft a prototype Patient's Bill of Rights for cancer care in Montana.
Strategy 3	Determine whether the implementation of a standardized Patient's Bill of Rights for cancer care should be initiated at the legislative or voluntary level, and promote implementation in the appropriate venue.

5 Wishes

The Five Wishes articulate your desires to your family and doctors.

1. Who you want to make healthcare decisions for you if you can't make them for yourself
2. What kind of medical treatment you want...or don't want
3. How comfortable you want to be
4. How you want people to treat you
5. What you want your loved ones to know



Cindy Peterson had a cough she couldn't shake, and she was short of breath. She tried antibiotics, but they didn't help. When she was still coughing the next week, she asked for another prescription. Instead the doctor listened very carefully to her chest.

"I don't like the way that sounds," he said. "I want you to get an X-ray right now."

Cindy had the X-ray. And then another. Shortly after that, they drained two liters of fluid from her lungs. Cindy is a nurse, and the color of the fluid terrified her. The only time she'd seen fluid that color, it had been in a patient with metastatic cancer. The doctor really didn't need to give her the news. She already knew. When he came into her office the next day, she started to cry as soon as he shut the door. Her doctor referred her to a gynecological oncologist in Spokane. They

scheduled surgery immediately. Cindy was in the hospital for a week, then came back to Montana for chemotherapy.

In the meantime, she started educating herself. She didn't have any illusions: the literature was grim. She had stage IV ovarian cancer, and the five-year survival rate was five percent. Cindy joined a clinical trial right away, and received excellent treatment from her doctor in Great Falls. It's now been two and a half years since she first learned that she had cancer.

Cindy has always had a positive outlook on life. Even though the cancer diagnosis was hard to accept, she knew she had to face the challenges ahead. Her choices were to accept the fate the statistics dictated, or take control of her own fate and defy the statistics. She chose to take control. She started small, by setting attainable life goals. She wanted to see her kids graduate from college. Now she wants to see her kids get married and to spoil grandkids. After that, she says she'll set new goals.

"Be informed, not afraid. A positive attitude helps. Educating yourself helps, too. The internet is a wonderful tool — use it to inform yourself, but don't just accept everything you read. No matter how bad the odds are, there are exceptions. People do survive. And if it isn't about survival, it's about quality of life. Don't look for death, look for life. I really started looking at the three Fs differently — Faith, Friends, Family. I need my family to get through this, and my family needs me. I intend to be there for them." — Cindy Peterson

What is a Durable Medical Power of Attorney?

A legal document that allows an individual the opportunity to legally authorize a trusted family member or friend to make healthcare decisions at such time as s/he can no longer do so. The Durable Medical Power of Attorney goes into effect immediately after execution and delivery to the agent, and remains in effect until terminated or revoked.

The Patient's Bill of Rights

1. **Information disclosure:** You have the right to accurate and easy-to-understand information about your health plan, healthcare professionals, and facilities.
2. **Choice of providers and plans:** You have the right to a choice of healthcare providers who can provide access to appropriate high-quality health care.
3. **Access to emergency services:** If you have severe pain, an injury, or sudden illness that convinces you that your health is in serious jeopardy, you have the right to receive screening and stabilization emergency services whenever and wherever needed, without prior authorization or financial penalty.
4. **Participation in treatment decisions:** You have the right to know your treatment options and to participate in decisions about your care. Family members or your designees may represent you if necessary.
5. **Respect and nondiscrimination:** You have the right to considerate, respectful, and nondiscriminatory care.
6. **Confidentiality of health information:** You have the right to talk in confidence with healthcare providers and have your healthcare information protected. You also have the right to review, copy, and request corrections to your own medical record.
7. **Complaints and appeals:** You have the right to a fair, fast, and objective review of any complaint you have against your health plan, doctors, hospitals, or other healthcare personnel. This includes complaints about waiting times, operating hours, the conduct of healthcare personnel, and the adequacy of healthcare facilities.

— Adapted from the Patient's Bill of Rights used by the U.S. Advisory Commission on Consumer Protection and Quality in the Health Care Industry. — www.cancer.org

Goal III: Ensure childhood cancer survivors are provided age-appropriate services.

Objective III.1: *Establish and implement methods to assist school administrators, teachers, and students with the unique challenges presented by children with cancer and their siblings.*

Baseline: There is no consistent approach by schools for addressing the needs of children affected by cancer

Outcomes: By 2010, define and implement methods for addressing the educational needs of children affected by cancer

Data sources: Process evaluation results

Strategy 1	Identify the challenges and emotional needs of children with cancer, their siblings, and families correlated with school reintegration activities.
Strategy 2	Research best practice models and develop age-appropriate methods to address identified educational needs.
Strategy 3	Develop creative alternative education plans for children cancer survivors.
Strategy 4	Develop and provide in-service training and continuing education opportunities for educators who work with childhood cancer survivors and their siblings.

Objective III.2: *Identify the non-educational needs unique to children with cancer and their siblings.*

Baseline: A children's special needs resource list has not been identified

Outcomes: By 2010, develop, distribute, and maintain a children-with-cancer special needs resource list

Data sources: Process evaluation results

Strategy 1	Establish a committee to identify the non-educational needs unique to children with cancer and their siblings.
Strategy 2	Develop and routinely update a comprehensive list of the resources available to pediatric cancer patients in Montana, such as specialty services, wig programs, camps, scholarships, wish-granting organizations, and home health agencies. Add the resource list to the <i>Cancer Resource Roster</i> on the Cancer Control webpage.
Strategy 3	Determine existing resource and service gaps and develop strategies to address the disparities, overcome the barriers, and fill the gaps.
Strategy 4	Develop an information distribution plan to reach all newly diagnosed pediatric cancer patients and their families.

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.

How to Help Children with Cancer in Your Community

- Support local fundraisers.
- Volunteer your time to local nonprofits that work with children who have cancer.
- Advocate for the state and federal policies that will assist children with cancer and their families with their travel and treatment needs.

Goal IV: Ensure that there are opportunities for safe and effective use of complementary medicine in cancer care in Montana.

Objective IV.1: *Increase patient, healthcare provider, and institutional awareness of the available complementary therapies from which cancer patients have been shown to benefit.*

Baseline: No baseline data describing the level of awareness of complementary cancer therapies is available

Outcomes: By 2008, determine how many accredited educational presentations on complementary cancer therapies are available

By 2011, increase the number of accredited educational presentations on complementary cancer therapies by a percent to be determined

Data sources: To be established

Strategy 1	Conduct a study to determine how many accredited educational courses that address complementary cancer therapies are available to Montana survivors, healthcare providers, and institutions.
Strategy 2	Educate allopathic/osteopathic healthcare providers on potential contributions of complementary and American Indian therapies in cancer care.
Strategy 3	Educate patients on the potential harm associated with self-prescribed care.
Strategy 4	Educate allopathic/osteopathic healthcare providers and patients about the difference between licensed and unlicensed complementary care providers.
Strategy 5	Establish a method whereby allopathic/osteopathic providers and patients can easily identify and access licensed naturopathic providers as well as other licensed or certified complementary care providers.
Strategy 6	Develop tools to improve communication between complementary healthcare providers and allopathic healthcare providers, and educate cancer patients to communicate information about medications, care plans, and supplements to all their healthcare providers.

Naturopathic physicians are licensed in Montana as primary healthcare providers. They have broad training and can contribute and participate in many aspects of cancer care, such as data collection, early detection, integrative treatment, quality of life, research, and advocacy. By utilizing the naturopathic physician's expertise in nutrition, lifestyle modification, environmental health issues, and health maintenance, cancer prevention can be maximized.

The **American Cancer Society** recognizes the need to balance access to complementary therapies, while protecting patients from methods that might be harmful. The ACS supports patient access, but strongly encourages oversight and accountability.

Quality of Life & Survivorship: What You Can Do

- Talk to your healthcare provider about your goals and values for end-of-life decisions, your treatment, and concerns about symptoms and pain management.
- Complete and communicate an advanced healthcare directive.
- Educate yourself about your disease and know what to expect.
- Understand the Patient's Bill of Rights.
- Support expansion of hospice care availability in frontier and American Indian communities and support programs that enhance quality of life for cancer patients.